



**Nevada Commission  
On Autism Spectrum Disorders**

*Addressing issues across the lifespan*

# Strategic Plan

2015 - 2020



## Acknowledgements

This page recognizes the individuals who lead or participated significantly in the planning process or in the development of the plan.

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## Executive Summary

This section summarizes the key information from all of the other sections of the strategic plan down into a 3-4 page executive summary. It will be written so that an outsider can easily read and understand the mission of the Commission, its overall major issues and goals, and key strategies to reach the goals.

## Background and Introduction

### Commission on Autism Spectrum Disorder

The Nevada Commission on Autism Spectrum Disorders (herein referred to as “Commission”) was established through Executive Order in 2008 by Governor Jim Gibbons, and amended by Governor Sandoval in 2011. It is structured to include a composition of five members, appointed by the Governor, which includes representation from the school system, an expert in behavioral analysis, a member of the general public, and two parents of children with an autism spectrum disorder.

The work of the Commission is an extension of an effort that was started in 2007 when Governor Gibbons established the Nevada Autism Task Force. The task force was comprised of 14 individuals that met for a year to study and make recommendations regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the state. The result of their efforts is contained in the 2008 Report of the Nevada Autism Task Force: An Action Plan For Nevada’s Legislators and Policy Makers. This final product of the workgroup contained 146 specific recommendations regarding the appropriate response to autism in the state of Nevada. The primary task of the Commission is to “continue the work of the Task Force by developing strategies to implement, to the extent possible, the recommendations made by the Task Force.”

Since its establishment in 2008, the Commission and its established Subcommittees have worked to make progress in implementing the recommendations of the Task Force. Some legislative accomplishments include:

- Passage of AB 162, which requires insurance policies to offer an option of coverage for the screening, diagnosis, and treatment of autism spectrum disorders for individuals under 18 or up to 22 years old if enrolled in high school.
- Passage of SB 359, which requires employees and contractors of Early Intervention (EI) to perform screenings for autism at the age levels and frequency recommended by the American Academy of Pediatrics. This bill also established a training and education component for individuals in the school systems and in EI that work with children and families facing autism.
- Passage of AB 313 & AB 345, which established the Autism and Treatment Assistance Program (ATAP) within the Aging and Disability Services Division (ADSD) as Nevada's Autism Program, placing them in Nevada Statute. The legislation requires the establishment of statewide standards, and the data collection and annual reporting of the number of individuals with Autism Spectrum Disorder (ASD) as well as services rendered.

While progress has been made, there is still plenty of work to be done. The prevalence of ASD and the number of Nevada residents impacted continues to rise at a rate surpassing the availability of supports and services needed. Recognizing this reality, the Commission embarked upon a strategic planning process to explore and confirm the most pressing needs of individuals with ASD across the lifespan and to establish a five-year plan to guide the Commission in responding to those needs.

### Organization of the Report

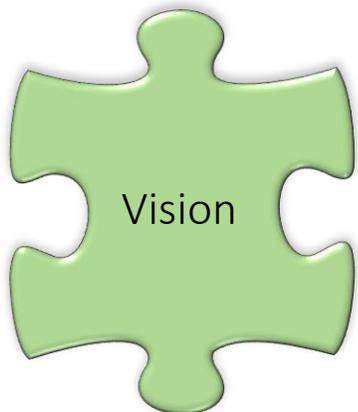
The report is comprised of the following seven sections.

<b>Executive Summary</b>	This section summarizes the key information from all of the other sections of the strategic plan into an executive summary. It provides a high level overview of the mission of the Commission, its overall major issues and goals, and key strategies to realize those goals.
<b>Background and Introduction</b>	This section provides background information about the commission and the purpose of the plan. It provides context and historical perspective leading up to the development of the strategic plan.
<b>Strategic Orientation</b>	This section presents the vision, mission and values held by the Commission. This framework is what is used as the “looking glass” through which all decisions related to the Commission are made.
<b>Methods</b>	This section presents the methods and the approach to the strategic planning process through each phase of development.
<b>Situational Analysis</b>	This section of the report describes the current reality of individuals with ASD in each stage of life for residents throughout Nevada. It explores the most pressing needs facing the population, as well as strengths and weaknesses of the service system.
<b>Goals and Objectives</b>	This section lists the goals of the Commission over the 2015-2020 timeframe. It also provides specific objectives that will be pursued and the benchmarks to measure success or the need to modify thier approach.
<b>Updating the Plan</b>	This section describes how the Commission will measure and report on its success and lessons learned. Specific milestones for assessing progress are described and the frequency for reporting and discussing results.



## Strategic Orientation

The Commission functions within the framework of the following vision, mission and guiding principles.



*All Nevadans living with autism spectrum disorder will reach their full potential.*



*The Nevada Commission on Autism Spectrum Disorders mission is to provide **leadership, oversight and legislative advocacy** in support of Nevadans living with autism spectrum disorders.*



**Information:** Every person living with ASD and their families deserves timely access to appropriate information about available services regardless of their individual circumstances.

**Choices:** All Nevadans with ASD have the right to self-determination and should be afforded the right to define home, community, independence and outcomes for themselves, in their own terms.

**Access:** Timely diagnosis and interventions that are evidence based and provided at the appropriate levels are critical to helping people with autism reach their full potential.

**Support:** Primary and secondary providers should deliver a coordinated, comprehensive and standardized system of care that embraces a person-centered framework throughout the lifespan.

**Respect:** As a vital part of the service system, families have different needs, expectations, resources, values, and priorities, which must be honored in the service delivery process.

**Fidelity:** All professionals should utilize evidence-based practices and regularly evaluate the effectiveness of interventions used.

## Methods

To develop this strategic plan, a three-phased approach was used to include: Phase I – Data Collection and Assessment; Phase II – Identification of Critical Issues; and Phase II – Establishment of the Strategic Plan. The three phases took place between August 2014 and December 2014.

### Phase I – Data Collection and Assessment

The initial phase of the project involved development of the Strategic Planning Steering Committee which would serve to support and oversee the strategic planning process. The group included all members of the Commission on Autism Spectrum Disorder as well as the Chair of each Commission Subcommittee and a leadership representative from the Aging and Developmental Services Division (ADSD). The Steering Committee was responsible for clarifying planning questions, identifying critical issues, and developing strategic goals and objectives.

During the first 2 meetings with the Steering Committee, a research plan and outreach approach was approved, which established the framework for initial data collection. The data collected was meant to confirm the key needs of individuals living with autism, and to explore what areas within the existing system should be expanded, changed, discontinued or legislated to better meet current and future needs of these individuals. There were four data collection methods used to solicit stakeholder feedback. They included key informant interviews, Commission Subcommittee discussions, consumer surveys and provider surveys. Each is described more fully below.

#### Key Informant Interviews

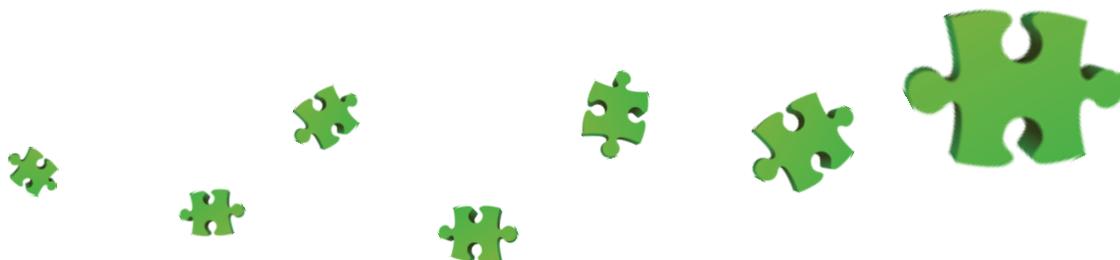
Key informant interviews were conducted as a mechanism to gather insight on the strengths and challenges related to the existing system(s) for individuals with ASD. Between September 8<sup>th</sup> and October 5<sup>th</sup>, 2014, 13 interviews were conducted with individuals identified by the Commission and each of the Commission Subcommittees as having specialized knowledge about the systems that provide services to Nevadans living with ASD throughout the lifespan.

#### Subcommittee Group Discussions

Between September and October, 2014 discussions were held with each of the Commission Subcommittees; Early Childhood, Youth and Transition, Adult and Aging, and Rural Populations. The purpose of these discussions was to gather perspectives and recommendations regarding priorities and strategies relevant to each subpopulation.

#### Consumer Surveys

Consumer surveys were issued to consumers, family members, care providers, and advocates to solicit input regarding the strengths and weaknesses of the current system as well as their suggested solutions for any identified deficiencies. Surveys were distributed through the Steering Committee, offering respondents the option of completing the tool either on-line through Survey Monkey, or in hard copy



form. A total of 399 surveys were collected from consumers across the state over a period of 31 days (August 22 – September 22, 2014).

#### Provider Surveys

Provider surveys were issued to organizations that provide direct services to individuals living with ASD throughout the lifespan. Surveys were distributed through the Steering Committee, requiring organizations complete the survey on-line through Survey Monkey. A total of 77 surveys were collected from ASD providers across the state over a period of 24 days (August 28 – September 20, 2014).



#### Phase II – Identification of Key Needs and Critical Issues

Input received through data collection efforts was analyzed to identify the key needs and most critical issues of individuals living with autism. Those critical issues were prioritized and served as the foundation for the establishment of the strategic goals contained in the plan.

#### Phase III – Establishing the Strategic Plan

The Steering Committee held three working meetings between October and December to finalize the strategic plan document, building specific goals, objectives and actions to be taken over the next 5 years.



## Situational Analysis

The following situational analysis was completed under the direction of the Steering Committee. Autism Spectrum Disorder definitions were taken from industry leaders, while prevalence data was taken from national statistics and applied to the Nevada population. This information was combined with key informant interviews, subcommittee group discussions, consumer surveys and provider surveys as a mechanism to identify the strengths, challenges and issues that the Commission on Autism Spectrum Disorder should consider for strategic plan action. The results of this analysis were used by the Steering Committee to prioritize critical issues and to guide the development of corresponding strategic plan goals and objectives.

### Definition of Autism Spectrum Disorder

Autism Spectrum Disorder, as defined by the Center for Disease Control (CDC) is “a group of developmental disabilities that can cause significant social, communication and behavioral challenges.”<sup>1</sup> The National Institute of Mental Health (NIH) declares that the symptoms associated with ASD can cause clinically significant impairment in social, occupational, or other important areas of functioning and that these symptoms vary in their severity by each individual.<sup>2</sup>

The term "Autism Spectrum Disorders" is often used to describe disorders that currently include autism, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

### Prevalence of the Issue

Prevalence rates of individuals with an Autism Spectrum Disorder (ASD) has increased significantly over the last 30 years, making it the fastest growing developmental disorder in the United States.

The most recent Center for Disease Control (CDC) estimates identify that 1 in 88 children have an autism spectrum disorder (1.1% of the population), while the National Health Statistics Reports estimate a prevalence rate as high as 1 in 50.

Using the more conservative estimate as offered by the CDC, the prevalence rate of 1 in 88 applied to the Nevada population of 2,554,359 suggests that around 28,098 people in Nevada have autism. This estimate does not recognize any prevalence variation among different age groups, as there are not any studies that recognize prevalence of ASD in older populations. Working with that limitation, the 28,098 estimate is simply being considered as a guideline for understanding how many individuals in Nevada may have autism.

*“My son has a unique way of looking at the world. Being that he has no way to verbally communicate I am locked out of his thoughts as he seems to be locked out of mine. He finds joy in the smallest of things; you can see it in his face. Be it from falling pieces of paper that he has ripped up into small bits or the sensation of running or clapping his hands.”*

Consumer Survey Respondent

<sup>1</sup> Downloaded on October 27, 2014 from: <http://www.cdc.gov/ncbddd/autism/index.html>

<sup>2</sup> Downloaded on October 27, 2014 from: <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>

Region/County	TOTAL POPULATION	Estimated Number of Individuals with ASD <i>(based on 1.1% prevalence rate)</i>
Rural and Frontier		
Churchill	23,526	259
Douglas	45,947	505
Elko	47,895	527
Esmeralda	825	9
Eureka	1,883	21
Humboldt	16,052	177
Lander	5,768	63
Lincoln	4,860	53
Lyon	49,176	541
Mineral	4,418	49
Nye	42,302	465
Pershing	5,115	56
Storey	4,009	44
White Pine	8,238	91
Carson City	52,257	575
<b>Regional Subtotal</b>	<b>312,271</b>	<b>3,435</b>
Northern		
Washoe	399,905	4,399
<b>Northern Subtotal</b>	<b>399,905</b>	<b>4,399</b>
Southern		
Clark County	1,842,183	20,264
<b>Southern Subtotal</b>	<b>1,842,183</b>	<b>20,264</b>
<b>Unknown</b>	<b>0</b>	<b>0</b>
<b>Nevada - Total</b>	<b>2,554,359</b>	<b>28,098</b>



## Systems Description

There are a variety of different systems in the state of Nevada that provide services to individuals living with ASD. Services throughout the state differ based on target population, geographic region and funding source. As a result, there are often different challenges for persons seeking assistance based on services available and where individuals try to access those services.

The system relies upon a variety of providers to include 1) primary providers, 2) secondary providers, and 3) linkage, advocacy, and coordination efforts. The following section summarizes each category. In addition, the strengths and weaknesses of the system are explored.

## Service Providers

### Primary Providers

Primary providers of ASD services in Nevada include state operated programs such as Nevada Early Intervention Services (NEIS), the Autism Treatment Assistance Program (ATAP), and the Regional Center Programs, all of which are managed within the Aging and Disability Services Division. Additionally, some

individuals with ASD are provided mental health services through the Division of Public and Behavioral Health (DPBH) as well as the Division of Children and Family Services (DCFS). Adults living with ASD may receive services through the Bureau of Vocational Rehabilitation (Voc Rehab) within the Department of Employment, Training and Rehabilitation.

Other primary providers of ASD services include school districts, non-profit/community based organizations and private practitioners.

### Nevada Early Intervention Services (NEIS)

Early Intervention services are provided to children from **birth to age 3** based on eligibility criteria. Services which may be provided includes; screening and diagnosis, therapy (psychological, occupational, physical, and/or speech and language), family training and counseling, nutritional counseling, and transportation.

### Autism Treatment Assistance Program (ATAP)

The ATAP program provides services to children **under the age of 19** with a diagnosis of ASD. ATAP offers a family budget depending on the child's age and allows families to select, hire, and bill their providers. The family is in charge of which services to utilize and when to schedule sessions. Individuals can stay on the program for approximately 7 years, 4 of which involve comprehensive services; the other 3 years focus on transition.

### Regional Centers

The Regional Centers provide services to individuals with intellectual and physical disabilities which include assistive technology supports, behavioral consultation, counseling, family support services, supported employment, nursing, nutrition, services coordination, transportation, community integration services, housing and supportive living arrangements (SLA).

### Division of Public and Behavioral Health (DPBH)

DPBH provides behavioral health services to adults in Washoe, Clark, and select rural communities through its rural clinic system throughout Nevada. It also provides behavioral health services to children and adolescents in rural health clinics throughout Nevada.

### Division of Children and Family Services (DCFS)

DCFS provides behavioral health services to children and adolescents in Washoe and Clark County.

### Bureau of Vocational Rehabilitation (Voc Rehab)

Voc Rehab employs counselors around the state, including JobConnect, a statewide network that connects businesses with employees. While Voc Rehab has no ASD-specific programs, it supports these individuals as a member of the disabled community. The BVR offers a range of employment services including assessments of job-related skills, assistance with job searches, job placement and retention, collaboration



with employers and agencies, transportation services, career counseling and guidance, and post-employment services.

Vocational rehabilitation services are available to high school students with disabilities that serve as a barrier to employment. Students do not need to be enrolled in special education services, and a separate evaluation is conducted to determine eligibility. Students either are referred to vocational rehabilitation or apply directly.

### School Districts

Special Education services are provided to children with disabilities (ASD included) through their local school district. A multidisciplinary team is tasked with establishing an Individualized Education program (IEP) which determines the supports that will be provided. School-based supports vary based on school district policy and resources, and are most deficient in the rural parts of the state.

### Non-profit and Community Based Organizations

A number of non-profit and community based organization provide services to individuals with ASD which include tutoring, day programs, recreation and leisure activities, support groups, respite care, housing and supportive living arrangements, just to name a few. These services are much more available and accessible in the two urban areas of the state, and the quality of care and capacity of each organization varies.

### Private Practitioners

Private ABA practitioners, Certified Autism Behavioral Interventionists (CABI's) and diagnostic providers are concentrated primarily in Washoe and Clark Counties. Access to these services often depends upon school system authorizations, Medicaid enrollment and health insurance approvals, and availability of providers.

### Secondary Providers

Beyond the primary providers, there are also demands placed on a number of other systems throughout Nevada that respond to persons with ASD. Secondary providers, such as emergency responders, hospital emergency rooms, law enforcement, primary care practitioners, and social services centers often come into contact with individuals with ASD. While many do not see themselves as providers of ASD services and are not fully equipped to address the complex needs of these individuals, they are part of a continuum of services providing access to care.

### Linkage, Advocacy and Coordination Efforts

Nevada has a number of collaborative, organizations workgroups across the state that seek to address systems improvement for consumers accessing autism specific and supportive services. These entities establish linkages, provide advocacy and promote coordination critical to an effective continuum of care.

### Commission on Autism Spectrum Disorder (CASD)

The Nevada Commission on Autism Spectrum Disorders was established through the Governor's office, and is tasked with implementing the recommendations of the 2008 Report of the Nevada Autism Task Force: An Action Plan For Nevada's Legislators and Policy Makers. The Commission provides a bi-annual report to the Governor, prior to the establishment of the bi-annual budget, providing an update regarding progress as well as a list of recommended actions to be taken by the legislature to better support the needs of individuals living with ASD in Nevada.

### Autism Coalition of Nevada

The Autism Coalition of Nevada is an advocacy organization, whose mission is to support legislation for appropriations which fund screening, diagnosis and treatment clinics for people with Autism. As a coalition, they:

- Provide a forum for ASD groups throughout the state to meet with each other,
- Combine resources to develop and implement autism awareness and advocacy,
- Provide information to and between agencies and other interested groups regarding conferences, seminars, meetings and other events, and
- Provide a communication network throughout the state to assist persons seeking information and referral.

### Families for Effective Autism Treatment

Families for Effective Autism Treatment, Inc. (FEAT) is a non-profit organization of parents and professionals, designed to help families with children who have received the diagnosis of ASD. FEAT offers a support network where families can meet each other and discuss issues surrounding autism and treatment options.

### Northern Nevada Autism Network (NNAN)

NNAN is a volunteer operated non-profit advocacy organization established to help families in Elko County affected by autism. The goal of NNAN is to increase autism awareness and access to treatment. NNAN is comprised of a diverse group of parents helping other parents, and dedicated to easing families' uncertainties as they navigate through the world of autism.



This complex system of primary and secondary service providers, supported by state and local coordination and advocacy efforts, serve a growing population of people being diagnosed with and recognized as having ASD. While the service population has grown, the availability of qualified staff and sufficient resources is insufficient to meet the demand. The following section describes the strengths and weaknesses of the service system as described by key stakeholders.

### System Strengths and Weaknesses

With a general understanding of the complex network of service providers that support individuals living with ASD, an assessment was conducted to explore what challenges exist within the system and to identify opportunities to leverage existing strengths. The following section provides a description of system strengths and weaknesses as identified by stakeholder outreach activities which included conducting key informant interviews with community partners, distributing surveys to consumers and providers, and facilitating focused discussions during Commission Subcommittee meetings with members and participants. The complete summary report for each of the outreach methods conducted can be found in the appendix of this report.

#### System Strengths

Key Informants and Subcommittee Group discussions described “pockets of excellence” where services and systems are functioning well, and offer an opportunity for the state to expand successful efforts. These are detailed below.

**University-Based Autism Programs:** Both the University of Nevada, Reno and the University of Nevada, Las Vegas are host to Autism Programs which serve to educate service providers, conduct research, and provide community based services to individuals on the spectrum. Both of these institutions were identified as a source of cutting-edge efforts for the state.

**ADSD Integration Efforts:** In the 2013 Nevada Legislature, a bill was passed that transfers Nevada’s Early Intervention Services (NEIS), previously within the Health Division, and Developmental Services (DS), previously within Mental Health and Developmental Services, into the Aging and Disability Services Division (ADSD). This was identified as an opportunity to develop a more streamlined approach to individuals with ASD as they will now be served by the same umbrella agency.

*“It is better than it used to be. ADSD is working on a single point of entry. We have purchased a data system that will help us link our systems. This is going to take time and lots of money, but we are moving in that direction.”*  
~ Key Informant

**Autism Treatment Assistance Program (ATAP):**

The ATAP program was identified as a significant strength for individuals living with autism, as a state sponsored program that offers services to this population. The program was identified as offering flexible services to meet the needs of its service population. It was identified as a model for expansion of services throughout the state.

**Strong Network of Family Support Organizations:** Stakeholders recognized the benefits offered by a variety of organizations that support families and individuals living with autism. These organizations provide services, support, and advocacy that is considered invaluable to the population.

*“We have an amazing advocacy community in Nevada among community based organizations and parent alike.”*  
~ Key Informant

**Size and Configuration of State Staff/Systems:** Stakeholders recognized that the configuration of state programs allowed easy access to state staff and leadership as well as provided for an agile and flexible approach to services.

**Commission on Autism Spectrum Disorder Advocacy:** Stakeholders, specifically key informants and the subcommittee groups recognized the efforts of the Commission, and identified that it has been extremely effective at advocating with the legislature to make significant progress in expanding services, establishing insurance solutions, and developing state level data collection efforts to continue to monitor the efforts of service provision.

Other strengths identified by Key Informants and Subcommittee Group discussions included the Lovaas Treatment Center, the VOICE program in Washoe County, the Governor’s efforts at establishing the Task Force on Integrated Employment, the TACSEI program, and the continuation of increased funding during each legislative session.

#### System Weaknesses

Stakeholders identified a number of weaknesses that need to be addressed to strengthen the system.

**Service Sufficiency:** All stakeholder groups identified a lack of sufficient services to meet the needs of individuals living with ASD throughout Nevada. This was described for all subpopulations throughout Nevada, although there was an emphasis provided in relationship to the more rural parts of the state.

**Financial Supports:** All stakeholder groups identified the need for additional financial supports necessary to address the various needs of individuals living with ASD. While stakeholders recognized the gains made through the ATAP program, they indicated that the amount of funding is still insufficient as wait-lists are significant. Significant criticism was levied against insurance products that either deny service claims or erect barriers to prevent access.

**Sufficient Workforce:** Nevada does not have a sufficient network of services/providers to adequately respond to the growing number of individuals with ASD. This results in a long-wait for services, and puts some people in a position to settle for services that are not high quality.

**Service Coordination:** Stakeholders describe a system that is fractured, and silo’d in its approach to serve individuals. Additionally, transitional supports are insufficient or deployed to late. While stakeholders described the current situation as being “better than it used to be” they still described the need for additional efforts in this area.

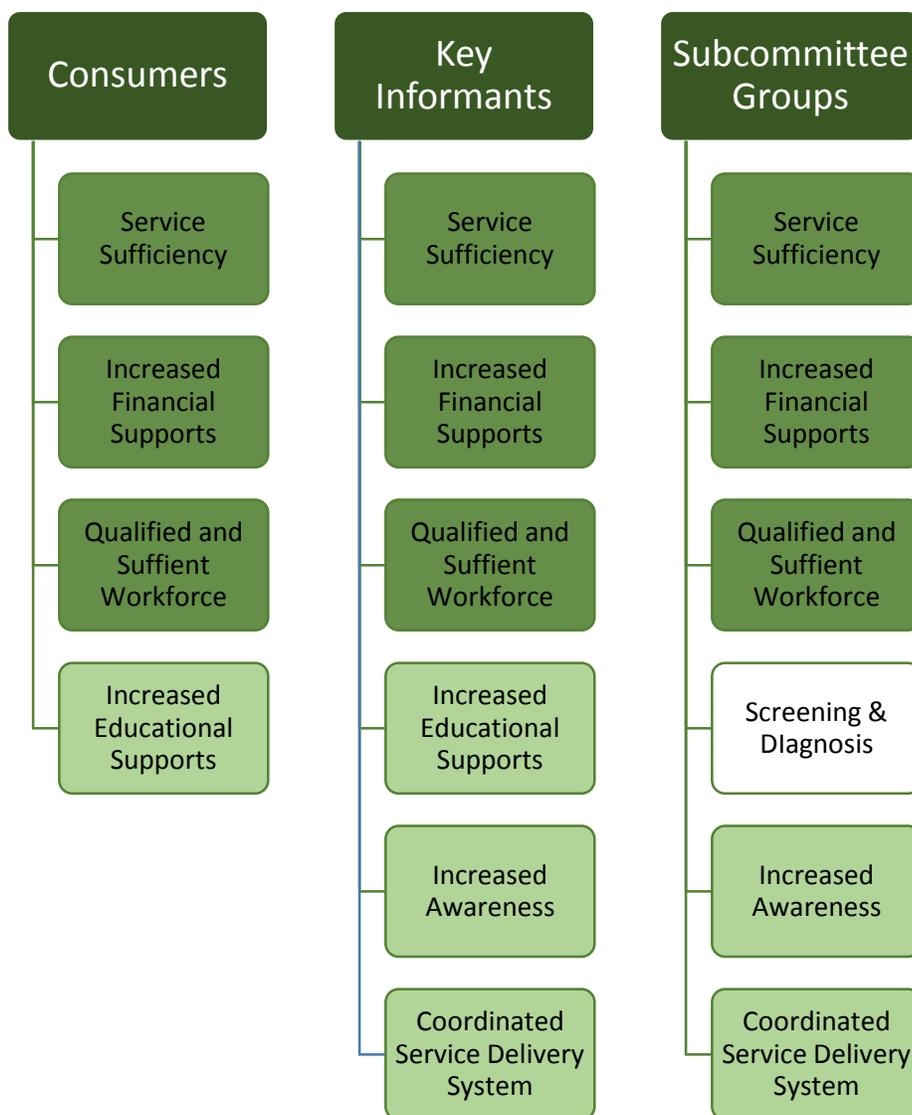
*“Service coordination is pretty poor from cradle to grave. It is a nightmare for parents. Different providers don’t work together, and many have different opinions. Parents have to work with multiple providers across many disciplines. Parents either have to take on service coordination themselves, or they back off and nothing gets done for their kids. At some point, parents may just give up, especially as these kids become adults.”*

~ Key Informant

### Key Needs

A number of consistently identified needs emerged from the analysis of all outreach conducted. In addition to cross-cutting themes that apply to the overall needs of individuals living with ASD in Nevada, there are also themes that are specific to targeted populations such as early childhood, youth, adults, and those living in rural and frontier areas of Nevada.

The chart below identifies the needs that were ranked as most significant for individuals across the lifespan according to stakeholder group.

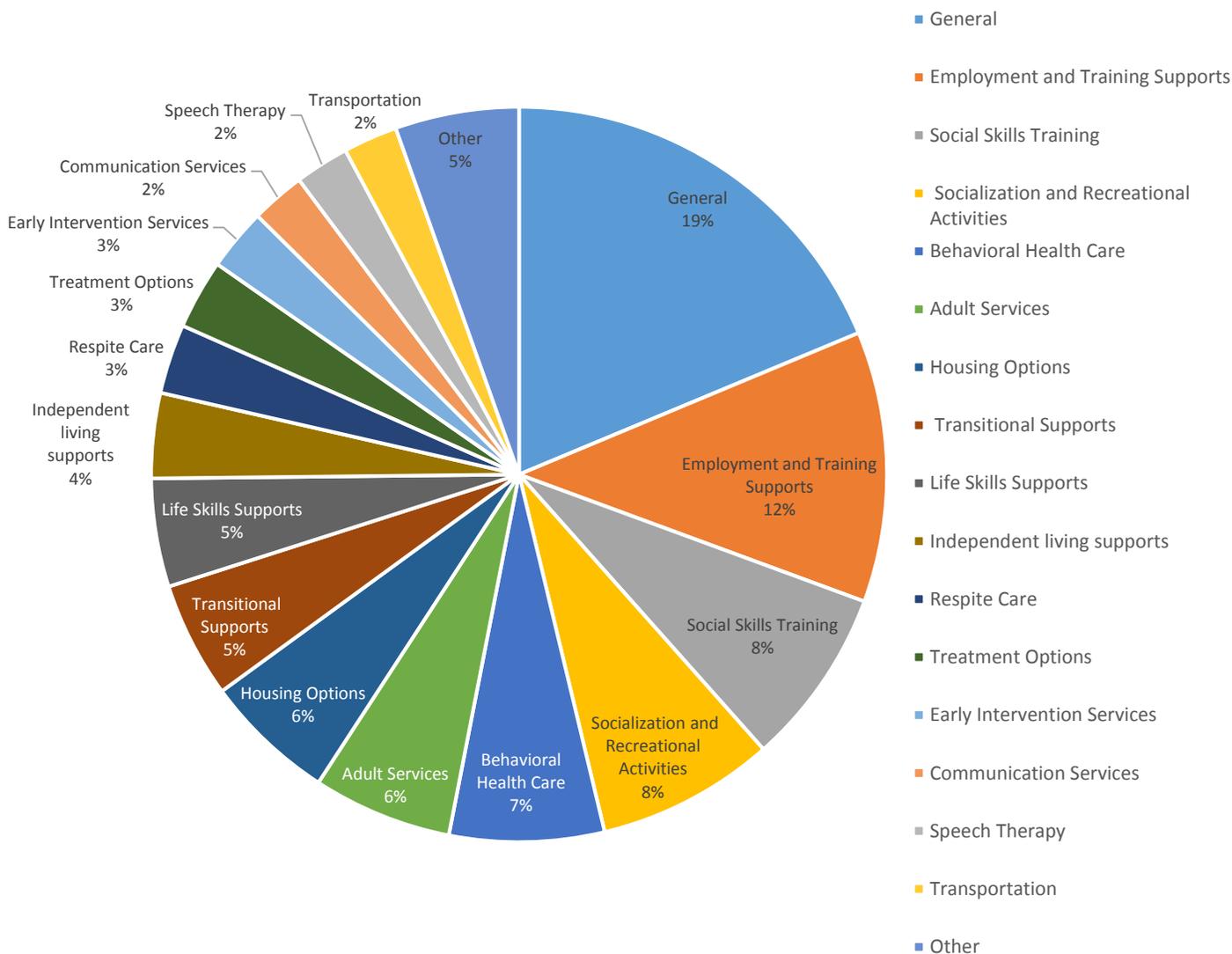


The three needs identified by all three stakeholder groups (key informants, subcommittee groups, and consumers) were the need for more services and programs, additional financial resources/support, and an increased workforce. Areas of need that were identified by at least two of the three stakeholder groups included Increased Educational Supports, Increased Awareness, and increased coordination across service delivery systems.

Service Sufficiency

Individuals living with ASD require sufficient services to meet the variety of needs that present themselves across the lifespan. Services such as applied behavior analysis, therapy (occupational, speech, and physical), physical and behavioral health care, and assistive technologies were just some of the services identified by stakeholders. There was widespread discussion around the need for *timely* access to *community-based* service *options* at necessary *service intervals* to appropriately *support* individuals living with ASD *throughout the lifespan*.

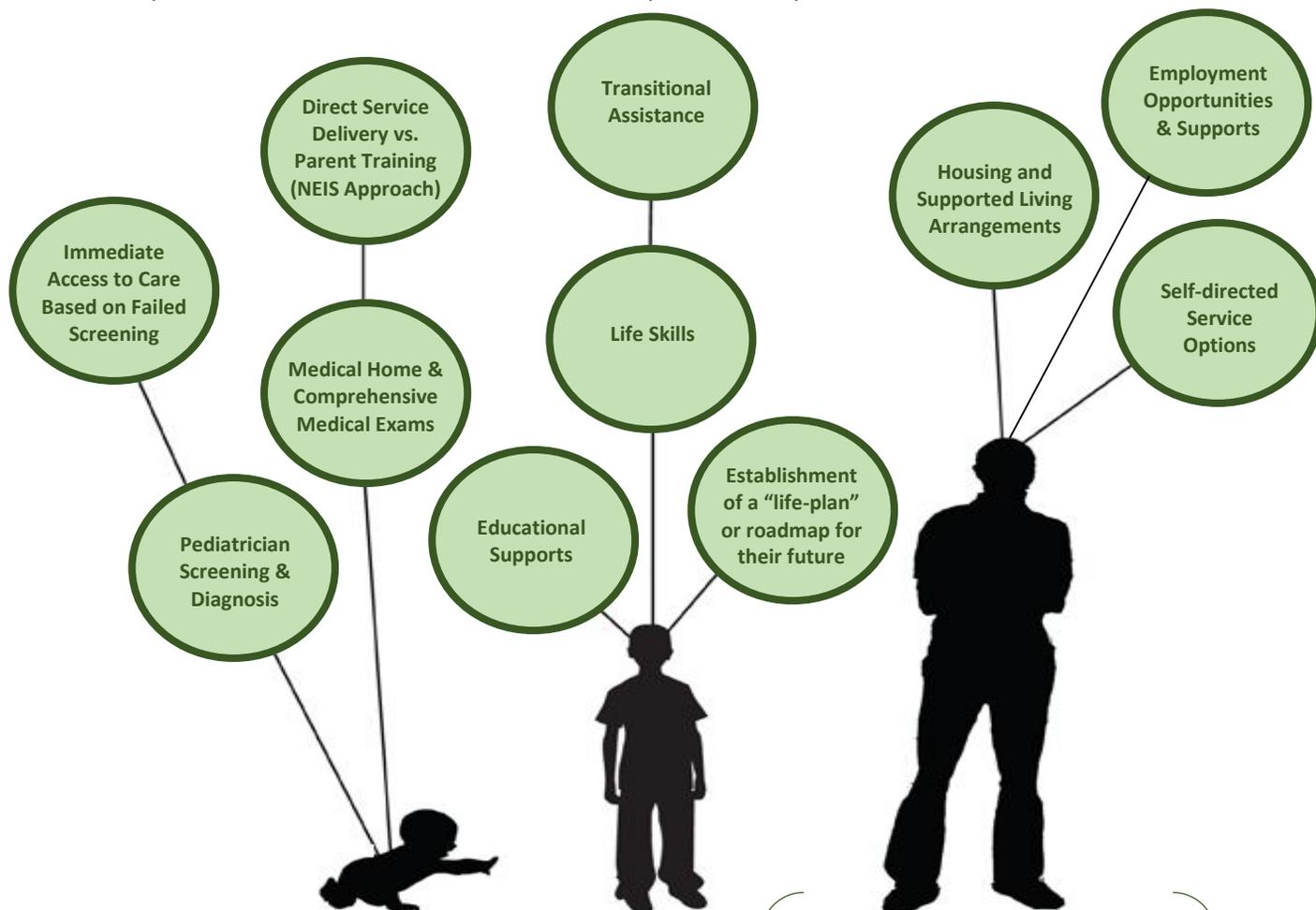
Consumers identified the following types of services most needed.



Information collected revealed that services for individuals with ASD, while insufficient throughout the lifespan, became more pronounced as individuals aged. Additionally, the more rural areas of the state were home to the least amount of service options, requiring many to travel far distances or choose to forgo treatment and risk loss of potential.

Service Needs that Were Particular to each Subpopulation

The following graphic is meant to demonstrate the service needs particular to individuals throughout their lifespan. There were needs that were consistently identified by both the Youth and Transition



Subcommittee as well as the Adult and Aging Subcommittee discussions, but not expressed as a concern for the early childhood community. These needs included:

- Recreational opportunities
- Transportation supports
- Assistance in accessing higher education; and
- Protection & safety skills.

The rural populations echoed all of which was identified by each of the other three subpopulations, emphasizing the exacerbating nature of each issue based on the lack of professional resources in the rural parts of the state.

*“The most significant need for individuals living with ASD is a supportive family network. People in rural Nevada often have to choose between having access to the support offered by family or access to care. When families have to move to access care, it is detrimental to the entire family structure as well as the individual living with autism.”*

Increased Financial Supports

All stakeholders identified the need to develop increased financial supports to support the affordability of services. Issues noted included:

- **Insufficient Insurance Coverage** was a common barrier to accessing care. All groups cited the difficulty in navigating health insurance systems (both public and private products) for coverage of ASD services. In many cases, even when insurance coverage provided some level of care, it was not sufficient to meet the needs of individuals with ASD and/or the co-payments were outside of what individuals/families can afford to pay.
- **Reimbursement Systems** are sometimes in place which require individuals to pay for services up front and wait for reimbursement. This is often not feasible for individuals/families.
- **Competing Financial Priorities** may hinder access to care, as some individuals/families do not have the luxury of taking time off of work to attend scheduled treatments.

Qualified and Sufficient Workforce

All stakeholder groups identified the need for a qualified and sufficient workforce to assist and support individuals living with ASD throughout the lifespan. Data collected identified the need for primary providers as well as secondary providers that were skilled and knowledgeable about ASD and the best approach to providing services to this specialized population. In addition, there was widespread recognition for the need to develop a sufficient and consistent workforce throughout the state to ensure timely access to care, and an array of service provider choices.

*“People with ASD need to have access to a qualified and consistent workforce who provide supportive services to them. Turn-over in the field is significant because of the low wages and insufficient training provided. This is very disruptive to our population.”*

Increased Educational Supports

Stakeholder groups identified the need for sufficient and consistent support provided through school districts, and a need to coordinate services between school systems and other providers. Stakeholders identified that Schools are not currently structured to fully support individuals with ASD. They do not have sufficient funding to provide the necessary supports, interventions, or ASD specific training of administrators, faculty and staff.

Increased Awareness

Stakeholders addressed the need for an informed and educated public as well as information related to the services available for individuals with ASD and how to navigate the systems providing those services. There was a consistent theme of families having to “fight” to understand what they are entitled to, and how to access appropriate care.

*“We need people to understand what ASD is and what it is not. We need a public that is educated. We also need to educate individuals and families about where they can go to for help.”*

### Coordinates Services Delivery System

Individuals on the spectrum may require services from a variety of different systems, concurrently and/or over the course of their lifetime. There is a need to have these various systems work in conjunction with one another to provide coordinated, and seamless person-centered care. Various applications, eligibility requirements, and benefits criteria behave as barriers and place the families in a position of having to become experts in a system that is largely responsive and silo' d in its implementation efforts.

### Screening & Diagnosis

The Subcommittee Group Discussions acknowledged the need to identify individuals living with ASD throughout the lifespan with appropriate screening and diagnostic resources. While the early childhood group described the need to screen and diagnosis as early as possible, with a preference for use of the American Academy of Pediatrics guidelines, the other groups insisted on the need to establish routine periodic checks to identify individuals who may have been over-looked, have had their condition or needs change over time, or those that have been inappropriately diagnosed with an alternative or co-occurring condition.

## Goals and Objectives

## Plan Updates

This section describes how the Commission will measure and report on its success and lessons learned. Specific milestones for progress are described, along with the resources and tools needed to conduct evaluation, and the method and frequency for reporting and discussing results. It also describes the process and timing for reviewing and updating the strategic plan document to reflect significant changes over time.

# Appendices

## Key Informant Summary Report

## Consumer Survey Summary Report

## Subpopulation Summary Report

## Nevada's Historical Commitment to Autism Spectrum Disorder

### 1997

- Clark County School District began funding ABA home programs.

### 2002

- Nevada Provider Rates Task Force Strategic Plan includes findings for Services for Individuals with Autism

### 2004

- Nevada Early Childhood Autism Task Force develops recommendations for Early Intervention Services.

### 2007

- AB 629 passed, creating Nevada Autism Task Force and appropriating \$2M in general funds for Autism Services. Funding supports pilot to serve children across the spectrum.

### 2008

- Nevada Autism Task Force delivers Action Plan for Nevada's Legislators and Policymakers with 146 recommendations, 11 for immediate action. Governor establishes Nevada Commission on ASD.

### 2009

- Legislature approved additional \$3.2 million for autism services, bringing the total to \$5.2 million. Continues funding for autism self-directed programs for a total of 121 children.
  - AB162 passed, Nevada becomes the 11th state to enact *autism* insurance reform on May 29, 2009. Applies to small and large group health plans, and State worker Health Plan, governed by state law. Individual plans will have to offer an optional rider for autism coverage. To read the bill and view its complete history go to: <http://www.leg.state.nv.us/75th2009/reports/history.cfm?ID=345>
  - AB359 passed, The bill requires all children being evaluated at Nevada Early Intervention or its community partners for services be screened for Autism according to the American Pediatrics Association recommendations. Requires Nevada Early Intervention to notify parents immediately if their child is found to be at risk of autism and refer child for a diagnosis and treatment. ·Requires the staff, who serve children with Autism within the Nevada Early Intervention or its contractors to provide parents with accurate information on autism and evidence-based treatments. ·Lays out a foundation of skills paraprofessionals should acquire to work with students with autism. Requires school district staff to refer to the 2008 Autism Task Force document when designing programs

for students with autism. You can read the bill and its history by going to:  
<http://www.leg.state.nv.us/75th2009/reports/history.cfm?ID=709> .

## 2011

- AB 345 passed establishing Autism Treatment Assistance Program (ATAP) as primary treatment program – funds transferred from MHDS self-directed autism program.
  - FY 12 ATAP slots = 134
  - FY 13 ATAP slots = 137
  - 174 additional children served through MHDS program
  
- AB316 passed, requires a statewide standard for measuring outcomes and assessing and evaluating persons with autism spectrum disorders through the age of 21 years for the purposes of receiving services. Requires the Division to designate, as part of the statewide standard, a protocol for determining whether a person is a person with autism spectrum disorder. Requires the Division to collect certain information relating to persons with autism spectrum disorders and to document the services provided to and the progress of those persons. **Surveillance Improvements** - Requires the Department of Education, the Health Division and the Department of Employment, Training and Rehabilitation to report to the Aging and Disability Services Division information relating to persons with autism spectrum disorders. You can read the bill and its history by going to: <http://legiscan.com/NV/text/AB316/2011>

## 2013

- Autism Treatment Assistance Program received \$11.7M over the biennium through general fund and tobacco settlement dollars
  - FY 14 slots = 307
  - FY 15 slots = 572

## 2014

- Interim Finance Committee funded \$113,000 to support Nevada Commission on Autism Spectrum Disorders and the Development of 5-year Strategic Plan to address the needs of Individuals with ASD across the Lifespan. Work begins on the plan July 2014, with the goal of completion of December 2014.
  
- The Legislative Committee on Health Care voted to support the following and address during the 2015 Legislative Session:

Draft a Letter to the DHHS encouraging the Department to:

1. Develop mechanisms to provide readily available access to the Modified Checklist for Autism in Toddler screenings that assess risk for autism spectrum disorder in rural Nevada and a mobile diagnostic clinic for those who have red flags identified by the screenings. In rural Nevada, accessing a diagnostic evaluation is a significant barrier to treatment.

2. Allow Autism Treatment Assistance Program (ATAP) funds to be used to support diagnostic clinics across rural Nevada, if it is determined to be feasible and appropriate. (Recommendation Nos. 18a and 18b proposed by Korri Ward, B.S., Founder and President, Northern Nevada Autism Network)

c. Encourage coordination between ATAP, Nevada Early Intervention Services, and rural school districts with the intent of promoting autism diagnoses, treatment, and helping coordinate providers and services to increase access to treatment and services in rural communities.

d. Require Nevada Medicaid to cover Applied Behavior Analysis (ABA) services as soon as possible by:

- i. Seeking clarification from Centers for Medicare and Medicaid Services regarding whether ABA can be included in the Nevada Medicaid State Plan via a plan amendment;
- ii. Preparing and submitting such an amendment;
- iii. Initiating the process of certifying providers of ABA services and establishing rates;
- iv. Providing ABA services to Early Periodic Screening Diagnosis, and Treatment children;
- v. Making the necessary request to shift available funding during this biennium to cover these services; and
- vi. Developing a budget for the next biennium that includes sufficient funding for Medicaid coverage of ABA and to eliminate the ATAP waiting list.

Revise the following provisions of NRS related to autism services and insurance coverage:

1. Remove the requirement that autism behavior interventionists be certified by the Board of Psychological Examiners. Instead, autism behavior interventionists will continue to work under the supervision of a licensed and Board Certified Behavior Analyst or a Board Certified Assistant Behavior Analyst but without their own certification. *Until 2017, at which time the National Registered Behavior Technician (RBT) will be required.*
2. Remove the requirement that an autism behavior interventionist be certified as a condition to insurance coverage for autism spectrum disorders. *Until 2017, at which time the National Registered Behavior Technician (RBT) will be required.*
3. Remove the statutory limitation of \$36,000 per year for applied behavior analysis treatment for consistency with the Affordable Care Act.